

Making a mockery of research

Neville W Goodman

It was obvious that the junior doctor sitting alongside me in the meeting was due to give a presentation later in the session. She was paying no attention to the speakers and took every opportunity when the lights came up to study the small pile of file cards clutched in her hand. Her lips moved as she read them to herself. During the time for questions after the third presentation she abandoned her file cards and sat rigid, chewing her lips. The speaker collected his prompts from the lectern and my neighbour stood up.

Considering her nervous state, she gave her presentation well. The tremble in her voice settled and though never at ease she didn't falter and was even able to ask the projectionist to improve the focusing of a slide. The study she was describing was mundane but there were no obvious flaws and she fielded the ensuing benign questions efficiently if not with any great skill or relish.

... a structure that is almost guaranteed to overproduce mediocre research.

She was clearly relieved when the chairman announced that it was time to move to the next speaker, and she resumed her seat next to me. Because she was one of five authors on the paper I asked her what she had done in the study.

"I took the blood samples," was her reply. No, she had not designed the study, selected the patients, or made any measurements. She had not done the statistics; she had not even written the abstract for the presentation. Yet what she did is called "doing research." She now has a publication on her curriculum vitae. This is a travesty and an all too common one. The curriculum vitae of registrars applying for senior registrar posts may give up to half a dozen "projects in progress," commonly on completely unconnected subjects. A colleague in another specialty told me of four registrars who, to bolster their "CVs," had all been coauthors on one another's papers. In a different specialty a registrar started in post at a "centre of excellence." He was somewhat surprised two weeks later to find his name on a paper for which the work had probably been completed before he had been interviewed for the post. At the least these last two incidents make a mockery of attempts to define authorship, but there are deeper issues than authorship to consider.

My neighbour at the meeting will remain

cynical about research; she has certainly learnt nothing about it. She will retain a memory of research as an unpleasant 15 minutes in the spotlight of a darkened lecture theatre. The episode shows abrogation of responsibility by her supervisors, whose main concern was to make their registrar salable.

And sometimes the behaviour of the supervisors is decidedly suspect. At another meeting a speaker was asked about the marked disproportion between the numbers of patients in each group in the trial. He guilelessly admitted that some patients had withdrawn: the withdrawals were all from one group and were after randomisation. The openness and lack of concern with which he gave his answer showed his unawareness of the bias this inevitably introduced. Yet, although some of the audience were concerned at this malpractice, the more general feeling was that the speaker was a bit unlucky to have been asked the question or, as someone later put it, "We all know there's a bit of a difference between what happens and what gets reported."

Is there? Must we read reports of clinical trials through wool pulled over our eyes by the investigators? If clinical trials are done with the aim of improving treatments then we owe it to our patients to put their needs before our lesser one of getting papers published. If the response to scientific transgressions is that most medical research is not worth reading anyway then we should stop forcing our juniors to do it. Juniors, if they do research, must be trained properly. If their supervisors have sloppy habits, and have contempt for reporting what they see in favour of reporting what they want to see, bad habits will be propagated.

* * *

The ultimate culpability lies elsewhere, in a structure that is almost guaranteed to overproduce mediocre research: academic clinicians are pressured into providing projects for uninterested juniors; pharmaceutical companies are keen to find clinicians to do "box fill" research for the companies' applications to the Committee on Safety of Medicines; and there are financial and other disincentives to applying for academic posts. It is unlikely that hospital managers, even less those whose hospitals opt out of central control, will have any motive for supporting any change. Hospitals get excellent value for money from academics: like other staff who hold part time clinical contracts they often work far in excess of their sessions. Then, when posts are frozen, they feel obliged to fill in rather than restrict services.

It would be difficult to provide evidence that research is good for junior doctors or that the ability to do research makes you a better clinician, although that does not prevent many from holding firm convictions about it. I have my doubts—equally firmly held and with a similar lack of evidence—but surely even the most ardent supporters of the

need for juniors to have their quota of publications agree that a system that begets these abuses needs some attention. Our preclinical colleagues often feel resentful of clinical academics and regard clinical research with sometimes barely concealed contempt. We do our cause no good by shrugging our shoulders as we enlist another unwilling junior.

Clinical medicine is not the only discipline that suffers from abuse in research: there is currently an argument in palaeontological circles about the "seeding" of fossils in obscure parts of the Himalayas. The realisation that we are not the only ones may prevent us from feeling too beleaguered or paranoid, but does not excuse casual abuses of research practice even if the results of the research are unlikely to do much more than bring satisfaction to the investigators for a job well done.

Neville W Goodman is a consultant senior lecturer in anaesthesia from Bristol

Colin's story

Surinder Singh

I first met Colin, a 32 year old Welshman, about six months ago when he was admitted to the new HIV and AIDS unit in central London where I was the medical officer.* I did not think too much about him then; he was a "routine respite admission," stayed for two weeks, and left without much ado.

Our second encounter was eight weeks ago when he walked into the unit having been transferred from a central London hospital. He had lost weight and looked generally worse. He had been in hospital for three days with shortness of breath, cough, and fever; a clinical diagnosis of pneumocystis carinii pneumonia had been made. He refused further treatment saying the medication was worse than the symptoms. I recalled that he had done this before his first visit to London Lighthouse, and at that time he had continued with homoeopathic treatment.

Colin was quiet, unassuming, and an extremely well dressed man who worked in the theatre in London. In fact he continued to work despite this recent setback. He admitted that the fevers were unsettling and disturbed him the most but he hoped he would be able to return to work quite soon.

The problem was that Colin did not want further "treatment." I say "problem" because he wanted very much to rest following the hospital admission but did not want any conventional medical intervention, even though he clearly had a pneumonia which was amenable to treatment. The fact that he had had only one previous opportunistic

*Colin is not the patient's real name.

infection meant that this episode could well be treated successfully, which would ensure a swift return to work and a good quality of life. He was not depressed, psychotic, or suicidal, he had just decided calmly that he would have no further orthodox medication. He knew the risks he was taking and he thought his decision was reasonable and well within the confines of rationality.

Many on the unit were asking what could be done to help Colin. Was his decision a rational one? Could we not try to actively treat him? What would happen if we just let him stay and seemingly did nothing?

* * *

What happened was this. He seemed fine for two weeks, but then became increasingly unwell with episodes of central cyanosis and fevers, but he remained free from pain. At no time did he want further intervention of any sort apart from his homoeopathic treatment, despite my efforts—and those of many of the other residential staff—to persuade him otherwise. On the 16th day, by which time he looked gaunt and very ill, he became quietly unconscious. Over the next 36 hours Colin's condition fluctuated quite markedly, ranging

from deep unconsciousness to being awake and responsive to his many friends. His mother commented to me that these friends, who had organised themselves to be with him at all times during the last few days, were his real family.

Are we unaccustomed to residents not wishing for active treatment . . . ?

My specific concern was whether these friends would want me to do something to try and prevent further inevitable deterioration, perhaps even intervene when he could not make a decision. All of his family and friends were extremely calm, however, and remained steadfast in their belief that Colin had reached this stage by remaining in control of his care and exercising his autonomy. They appreciated the support they received while on the unit citing Colin's previous admission to hospital as being extremely fraught and distressful to all concerned. Their commitment to ensure that Colin retained full control

throughout these last weeks and days was absolute.

Why was Colin's stay difficult for the unit? Was it Colin's autonomy which conflicted with the usual role of health care workers? Who defines rationality? Is it the resident or those caring for him while he was on the unit?

* * *

Are we unaccustomed to residents not wishing for active treatment when usually aggressive treatments are utilised well into advanced stages of disease? Our initial assessment suggested that Colin's condition was treatable and his chances of returning to work were high. Perhaps it was just very unnerving caring for a 32 year old man who has a treatable condition but who chooses not to be treated and who requires our support in exercising and implementing this decision.

All in all, Colin's apparent needs were met and his friends and family seemed resolved to his death.

Meanwhile the unit recovers and prepares for further routine admissions.

Surinder Singh is medical officer at the London Lighthouse

MEDICINE AND THE MEDIA

BBC 2 *First Sight*: "When Love isn't Enough"
17 January 1991

As full of grief as age

Marion Davies, a Scotswoman who loved Dickens, radio plays, and digestive biscuits, died from Alzheimer's disease. Her last illness would be familiar to millions in all its dismal details. She differed from most people, however, in having a journalist son, Hunter, and a novelist daughter in law, Margaret Forster—two public figures used in the programme to try and take a fresh look at a common enough situation.

Living alone in a cottage in Cumbria, Mrs Davies began to lose her short term memory and then to neglect herself, so that, in her son's words, "she looked like a witch, with unkempt hair, manic eyes, and clothes all over the place." The family moved her to live in a ground floor flat in Camden with her daughter. One night of her waking terrified, lost, and confused was sufficient, Margaret Forster said, "to make us see that we weren't made of the stuff that could survive that." Most of the burden of care, said the narrator, "therefore" fell on her daughter, although between them this family—described as robust and with the will, the know how, and the money—had to mobilise seven paid helpers in addition to themselves and some of their children too. With this army of carers—larger than any in my experience—they managed to keep the old woman at home until she had a fall, perhaps the result of a



Marion Davies

stroke, and was taken via the local district general hospital to the only place that would have her, the "Victorian lunatic asylum" at Friern Barnet; there, six months later, Marion Davies died, unable to see, speak, or hear, and, at the end, even to eat or drink.

This is a sad story and there was much grief on the faces of the Davies family and of others whose relatives were cared for in the hospital. The programme made its points well and clearly, using the practised articulacy of Margaret Forster to castigate not only present government policies of putting care back into the lap of communities largely without the means to do the caring, but also the wider Conservative philosophy of making indi-

viduals and families responsible for coping with what happens to them.

My main point of disagreement with the scriptwriters lies in their constant emphasis on the intellectual over the emotional: the theme was that if a person could not reason or communicate in words they were "dehumanised"—intellectual decline was the ultimate horror. Margaret Forster's contribution, which was the largest, strengthened this line, whereas there was no comment on a picture sequence from the hospital dayroom which showed an elderly couple, he perseverating meaninglessly, she leaning towards him asking for a kiss. Eventually he kissed her reluctantly and then moved quickly away, rubbing his face in embarrassment, at which she stroked his head lovingly.

This wordless example of communication by people who have lost the ability to speak remains for me the most vivid and lasting image from the programme. It reinforces the conviction I, as the doctor to a social care home for the elderly demented, have come to. There the staff, underpaid and undervalued and known demeaningly as care assistants—as though they didn't do *all* the work—put into practice something taken away from many doctors by the strong conditioning of their education: they know and value the continuing reality of their clients' emotional life and they realise that the withering of the intellect—even if it can at times be unbearably frustrating—is not necessarily the complete demise of a person as a human being. It was a pity that such a good programme seemed to miss this crucial point completely.—SIMON BARLEY, *general practitioner, Sheffield*